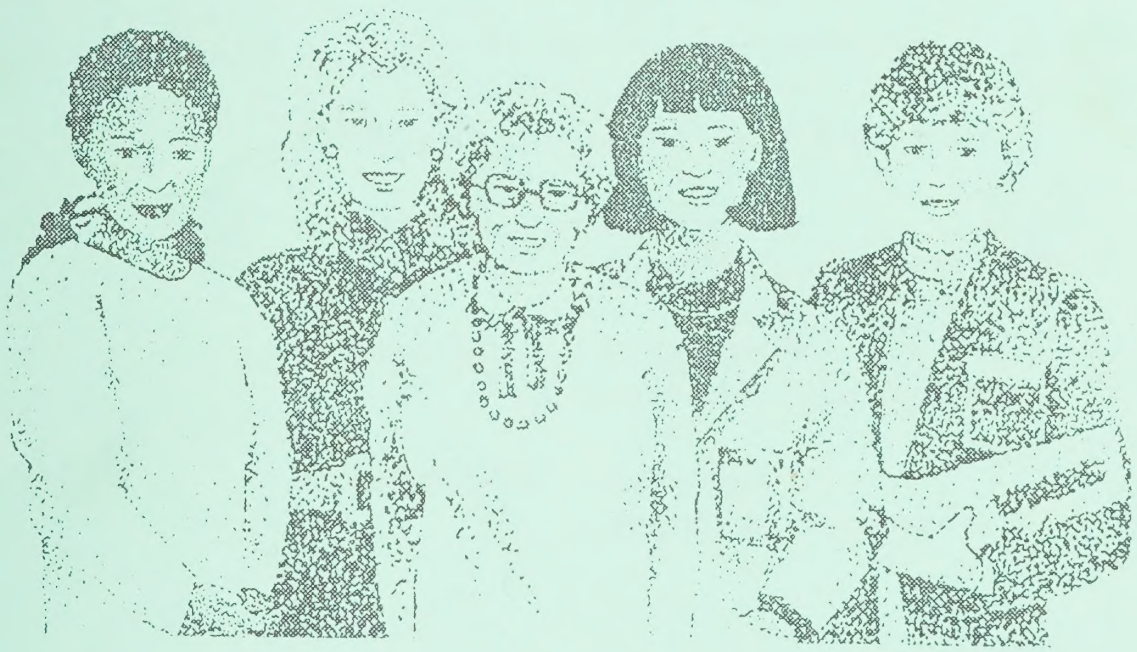
No Longer a Voice in the Dark

An assessment of the current resources for and concerns of female consumers in Hamilton-Wentworth



prepared
by Sheona Wilson

for the
Mental Health Rights Coalition
of Hamilton-Wentworth

May 1993

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Acknowledgements

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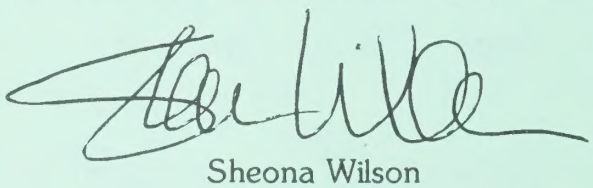


Sheona Wilson
Project Leader

About the Project Leader

Sheona Wilson has been a member of the Mental Health Rights Coalition since 1992. She has extensive experience working with children, adolescents and women in both advocacy and counselling roles. In 1986 she obtained a Child and Youth Worker Diploma from Mohawk College. She is currently in her third year at McMaster University working toward her BA in Sociology and a Bachelor of Social Work Degree.

Introduction

The Mental Health Rights Coalition of Hamilton-Wentworth is an organization dedicated to education, advocacy and empowerment for consumers of the mental health care system. During 1992, members of the Coalition were involved in discussions concerning services available to female consumers in the Hamilton area. Continually, concerns were voiced over the limits and gaps in services for consumers. Their observations were based on personal and professional experiences and knowledge gained from working in the mental health/social service systems.

From these informal discussions came a formalized proposal for funding to conduct research. "No Longer a Voice in the Dark" was undertaken by the Mental Health Rights Coalition (MHRC). The intent was to assess the current resources for and concerns of female consumers in the Hamilton-Wentworth area. The results of this assessment will enable the MHRC to respond to the specific, identified concerns of consumers involved with the mental health and social services systems.

The key issues in determining the scope of a woman's need for mental health services seems to be availability, affordability and appropriateness. Available and affordable that are inappropriate don't work. The more appropriate the services are for women, the longer the waiting list, because the bulk of the services are not specialized towards the needs of women.

"Mental Health Services for Women"
Anne McGrath
Healthsharing
Spring-Summer 92

The Provincial government policy document "Building Community Support For People: A Plan for Mental Health in Ontario" (the Graham Report) identifies the importance of mental health in the overall health equation and recognizes the connections involved between social, economic and physical factors.

> *"Traditionally, mental health policy has focused on issues related to mental illness and on the formal mental health care system. Institutional and community services have developed along parallel tracks. Community involvement in creating healthy environments and supporting the mentally ill has not been fully developed. This segregated approach has not served the needs of those with mental health problems or the mentally ill." (pages 16-17 of the Graham Report)*

Methods and Procedures

Information for this report was obtained from agencies in the Hamilton area, as well as female consumers of the mental health care system. Current literature on women and mental health was also reviewed for this report. Agencies were selected using The Directory of Community Services for the Regional Municipality of Hamilton-Wentworth. All agencies providing services to female clients, over the age of fifteen were asked to complete a standardized, mailed questionnaire (see appendix A and C). Some agencies provided service exclusively for female clients. Most, however, reported a female client base of fifty percent or higher. Also included in this survey were a number of family physicians who provide psychotherapy as well as out-patient psychiatric clinics in Hamilton area hospitals.

Some agencies chose to remain anonymous while others did not. For the purpose of this report, specific names of agencies will not be used. Agencies to whom the questionnaires were mailed represented the following areas of service: legal, financial/budget counselling, housing, employment, mental health, general counselling/psychotherapy, emergency shelter, drug and alcohol addiction counselling, vocational rehabilitation and general health care. Completed questionnaires were returned to the MHRC office or picked up in person.

Agency follow-up was conducted (by telephone) to obtain specific information including lengths of current waiting lists or fees for service. Completed questionnaires represent agencies who provide the following services: general medical care, counselling/psychotherapy, vocational rehabilitation and assessment, emergency shelter, twenty-four hour crisis lines, youth counselling, emergency transportation (ie to shelters), family violence education for the public and consumer, referrals, advocacy, support groups, employment counselling, correctional services and counselling and counselling and education on sexual assault, sexual abuse and violence against women.

Female consumers, from a membership list belonging to the MHRC were sent questionnaires to complete with an enclosed self-addressed stamped envelope. (see Appendix A and B) Consumer outreach was also undertaken to identify consumers in the general community and on the campus of McMaster University, who were also willing to complete the same questionnaire. In some cases, in-person interviews were conducted. These interviews followed the same questionnaire format. Information was also obtained through interviews with professionals working in the human services field and female consumers known to this writer. All consumers and interviewed professionals were assured anonymity.

Findings - Agencies

Based on information obtained from agency questionnaires and from interviews with professionals, the following areas were identified:

1. With the exception of an emergency shelter, no form of childcare is available to women using agency services

2. Locating appropriate, affordable housing for those with psychiatric disabilities and/or limited income is extremely difficult., At times the only option available is placement in a second-level lodging home.

3. Counselling for women, using a non-medical model is generally expensive and difficult to locate (for agencies, consumers and this writer). Fees for this type of service can range from $60.00 to $100.00 per hour. Some provide a sliding fee scale. The lowest fee found on a sliding scale was $40.00 per hour.

4. Waiting lists exist for many services. For counselling services using a non-medical model approach, waiting lists are extensive, ranging from several weeks for short term counselling to two years for long term counselling.

5. Those agencies who identified waiting lists, also identified a need for more services or expansion of existing services. This need was also identified by those agencies for whom waiting lists did not exist.

6. Only two agencies identified having a female consumer on staff. As many consumers admit to withholding psychiatric information from employers because of the stigma attached to mental illness, this number may be underestimated.

7. The estimated percentage of identified consumers (excluding agencies dealing exclusively with consumers) ranged from five to fifteen percent. Again, this may be underestimated.

8. Some agencies admitted to denying service to women based on their psychiatric background or diagnosis.

9. Academic requirements for those providing services to women ranged from none to post-secondary education including degrees in social work, nursing and medicine.

10. Agencies dealing exclusively with female clients offered on-going training and in-service education in the areas of domestic violence, violence against women, and housing. None of the responding agencies offered specific training or education on mental health issues and psychiatric disorders and their impact on women's lives.

Findings - Consumers

Based on information obtained from consumer questionnaires and from interviews with consumers, the following areas were identified:

1. Some consumers identified a lack of familiarity with the services available to them in Hamilton. Of those identifying this as an issue, most were unsure where to look for or how to access appropriate services. The remainder, were new to the Hamilton area, having been admitted to the Hamilton Psychiatric Hospital and were discharged into a community unfamiliar to them.

2. Consumers identified a lack of sufficient day programmes geared to those with chronic psychiatric disorders. Concern was also expressed that programmes geared to recreation, leisure activities and life skills development are insufficient.

3. A general concern was voiced that people in the "helping professions" treat consumers as merely a "psychiatric label". In particular, physicians and others in the medical field were viewed as treating women's difficulties as psychiatric symptoms only. Those agencies following a medical model were seen as unsympathetic to the other needs of women.

4. A major area of concern for nearly all respondents was the lack of services offered using an approach other than the medical model, especially regarding issues of incest and abuse. Appropriate therapists or agencies, once found, often have long waiting lists and are too expensive to be a viable option for most consumers.

The Canadian Mental Health Association (CMHA) document "Strategies for Change" describes the mislabelling of women's behaviour in ways that blame and devalue women. Victim blaming and misdiagnosis are entrenched in the system and the mental health community has absolutely failed to acknowledge the prevalence and impact of violence againt women.

"Mental Health Services for Women"
Anne McGrath
Healthsharing
Spring/Summer 92

5. Many consumers experienced waiting lists at most agencies. If they found themselves in a crisis situation, many felt they had no where to turn for assistance. Others obtained service where there were shorter waiting lists, or none at all (Hospital out-patient departments, for example). Sometimes however, consumers found these services to be inappropriate in meeting their needs.

6. Consumers identified a lack of gender-specific programmes dealing with issues such as drug and alcohol addiction, incest and emotional, physical and sexual abuse. Available services, again, tended to have long waiting lists, were too expensive or may have denied access to those with a clinical psychiatric disorder.

7. Some respondents stated they had been denied access to services such as emergency shelters and services providing incest and sexual abuse counselling. Some consumers were clearly advised that they were "inappropriate" for service because of their psychiatric background and/or diagnosis.

8. Housing is a concern particularly for consumers living on a fixed income. Opportunities to access appropriate and affordable housing are extremely limited. Because of this, many female consumers have been forced to live on the streets, to rely on family members, or have been placed, with limited consultation, in second level lodging homes. Additional concern exists for female consumer/survivors who, with limited choice, sometimes find it necessary to reside in unsafe or abusive situations. Female consumers with children or other dependents experienced additional housing difficulties. Overall, there is a lack of viable housing options for consumer/survivors.

9. Consumers also expressed concern regarding insufficient services to aid in the transition from hospital to community living, especially programs which would be geared to teaching socialization and independent living skills.

10. Some agencies were found, by consumers, to be inappropriate because they did not display an understanding of mental health and illness and its impact on women. Denial of access to services was felt to be a result of fear and misunderstanding about mental illness on the part of agency personnel.

Conclusions

Women experience depression twice as frequently as men and for one in ten women, this depression can be severe... women attempt suicide more often than men... women most at risk for depression are those at home with children under six.

"A Mental Health Plan for Hamilton-Wentworth"
Hamilton-Wentworth District Health Council
p. 177

A comparison of the responses from agencies providing services to female consumers and responses from consumers themselves identifies many of the same concerns.

The need for appropriate and affordable housing is a concern expressed by everyone. Individuals who could move toward semi-independent or independent living often find it difficult if not impossible to do so. With limited finances, consumer/survivors are often unable to make the transition from second-level lodging homes.

Residents of second-level lodging homes are generally unable to hone the skills required for living independently. Most home owner/operators do not provide opportunities for residents to cook, do laundry or manage their own medications. Residents, as a result, either do not have the confidence to move on or are not eligible for most subsidized housing programmes because of their psychiatric history and their limited life skills.

Consumers and agencies both clearly identified concerns regarding the availability of and differences between the medical model of treatment and the non-medical models of service provision. The medical model was viewed to be readily available but lacking a sensitivity to incest and sexual, emotional and physical abuse - issues identified as crucial by consumer/survivors. Non-medical services were viewed to be plagued with extensive waiting lists, high costs and limited knowledge of psychiatric diagnosis while displaying a greater sensitivity to other women's issues.

There is also an apparent lack of specific training or education for agency staff regarding mental health issues and psychiatric disorders,. Consumers were aware of this issue and they felt a lack of information or misinformation about mental illness had resulted in less sensitive treatment or a complete denial of services.

Overall, many of the concerns raised by both consumer/survivors and agencies are similar and revolve around the existence of gaps in current resources.
These issues include:

a) lack of childcare
b) limited housing options
c) lack of non-medical counselling,
d) limited educational programmes for service providers
e) limited existence of consumer education programs

Recommendations

1. Education

The design and implementation of education programmes on mental health and illness and their impact on women's lives is essential. Educating consumer/survivors, the community, families, health care providers, social agencies and government would help to ensure that women with psychiatric histories are guaranteed equal access to resources and that gaps in resources are addressed.

1.1 Consumer/survivors

Consumer/survivors must be educated about available community resources to allow them to be able to chose from and access appropriate services to meet their needs. Available information such as the Hamilton Psychiatric Hospital's "Little Yellow Pamphlet" must be made more readily available to patients upon discharge from hospital. All agencies should provide information to consumers so that all individuals are informed of what services are available and what criteria is used to determine programme eligibility. All agencies and service providers should ensure that staff are more aware of other community services, including consumer support groups, to guarantee that individuals will be directed to programmes appropriate for their needs.

1.2 Community

Educating the community is necessary to correct the misinformation and stereotypes which result in prejudice and discrimination against those with psychiatric histories which serves to restrict access by consumer/survivors to their own community. Psychiatric housing is frequently unavailable or restricted because of community attitudes. Misinformation regarding psychiatric illnesses, symptoms and behavior have resulted in a "not in my back yard" attitude, thus limiting available housing. Mental health professionals, consumers and agencies must work together to shatter these myths.

The ongoing delivery of the Hamilton Psychiatric Hospital's "Psychiatric Education Program, (PEP)" must be encouraged. The community, agencies and healthcare professionals need to access this program to generate a broader understanding of mental illness and consumer issues.

1.3 Family

Education is also imperative in providing families with the knowledge and information they require to provide support and understanding. Existing programmes geared to providing such information and support should be promoted and encouraged.

1.4 Health care professionals

Health care providers (psychiatrists, medical doctors, nurses and social workers) receive training and education in clinical psychiatry; however, they exhibit significant gaps in their understanding of the "human" experiences of mental illness and the impact it has on women's lives. Health care providers could benefit from an education package including both a clinical view and a consumer perspective.

1.5 Social Service Agencies

Social agencies could also benefit from an education package similar to that of health care professionals. Clinical education regarding psychiatric illness is essential in addressing the misinformation and fear which result in limited access and denial of services to consumers.

Planners for psychiatry services consider women's mental health needs specifically with respect to having a choice of caregivers who are sensitive to women's issues, such as sexual abuse, and having access to women psychiatrists and therapists as essential.

"A Mental Health Plan for Hamilton-Wentworth" Hamilton-Wentworth District Health Council, p. xvii

1.6 Government

Municipal, provincial and federal governments must become educated and enlightened regarding mental illness and female consumers and their needs. Informed politicians and governments can help ensure adequate legislation, funding and programmes to address mental health issues. Government awareness is necessary to guarantee ongoing commitment to second-level lodging home legislation, the Graham Report, the Lightman Report (the Report of the Commission of Inquiry into Unregulated Residential Accommodation) and the Family Benefits Act.

No sector of our community is unaffected by mental illness, yet as a community we continue to display an ignorance which impacts daily upon the lives of consumer/survivors. Ignorance can only be ended with education.

2. Service delivery

It is imperative that consumers have available a range of appropriate services. These must include services which address both the clinical aspects and the non-medical issues of women and mental illness. Neither approach alone is sufficient in meeting the needs of female consumers. A better understanding by all services providers must be ensured.

3. Abuse

Instances of abuse (physical, emotional, sexual) have been well documented as having a significant impact on the lives of women. Abuse can initiate, or exacerbate an existing illness, or undermine the effectiveness of treatment. There is a definite need for more available services that take into account the impact of childhood abuse on mental illness.

It is imperative that agencies assume a proactive position to prevent revictimization of consumers in hospital, second-level lodging homes or the community. It is necessary for all service providers to be constantly aware of the long term impact of childhood abuse on mental illness. They must be committed to ensuring that a consumer is receiving adequate treatment for these issues as well as symptomatic intervention for their illness.

4. Housing

The development of a number of housing options is necessary in order to respect the diversity of consumer survivors, their needs and their individual abilities. To not provide or encourage independent or semi-independent living would be to ensure that female consumer/survivors remain virtually powerless.

Access to existing housing must be ensured for consumer/survivors while also working to develop a range of housing options and programmes. The development of programmes and mental health/illness education for current housing agencies is indicated to broaden housing resources available to consumer/survivors.

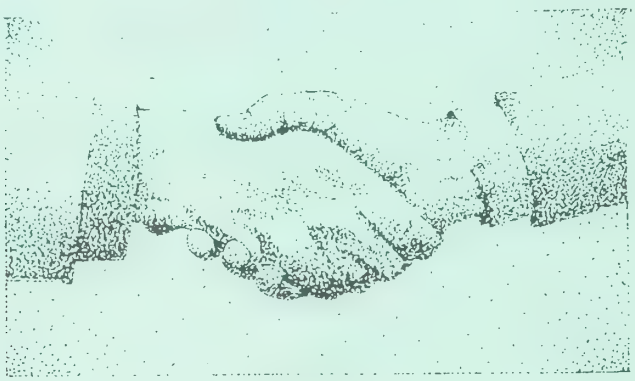
5. Further Study

This study is general in nature and more in depth research needs to be conducted into the specifics areas of concern identified in this report.

The Final Word

This study has just begun to address a wide range of issues for female consumers. Previously, many consumer/survivors lacked a forum to express their views. They also did not have an audience willing to listen. They had been given no platform and had no way to articulate their concerns. This work has only just begun to open the door to the many concerns and difficulties experienced by female consumer/survivors.

There are many who still do not feel comfortable in voicing their concerns. This will change in time and with effort as we are empowered to speak out. This research effort ensures that we are no longer invisible, nor are we silent...



We are no longer a voice in the dark!

It is hoped that this report will be used by the Mental Health Rights Coalition as a tool to stimulate a dialogue in the community on issues of interest to women. This dialogue will hopefully lead service providers, consumers and organizations like the Coalition to make a commitment to work together with women to make services more accessible, affordable and appropriate.

"No Longer a Voice in the Dark" provides the Mental Health Rights Coalition with the foundation and a direction for responding to the needs and concerns of female mental health consumers. Clearly, there is a need for both the community and the Coalition to join together in order to deal with the issues raised in this report.

Appendix A
Letters of introduction

Consumer Letter, February 23, 1993

Our intention for this questionnaire is to assess the current resources for and the needs and concerns of female consumer/survivors in the Hamilton-Wentworth area. The results of this assessment will enable us, at the Mental Health Rights Coalition, to address specific identified concerns of women involved in the mental health system.

In order to do this effectively, it is important that we hear from those directly affected by the resources currently available. We, as consumer/survivors, are the best resource we have to identify areas where there is a lack of service. Your participation in this survey is completely voluntary, but your input is greatly needed and would be appreciated.

Your name will not appear anywhere on this questionnaire. Your comments and answers will not identify you in any way in the completed report. Results from this assessment can be made available to you. Should you wish to obtain a summary of the results, please contact the Charlton St. office after April 1993.

Please send the completed questionnaire, using the enclosed self-addressed stamped envelope, by March 18, 1993. If you would like assistance with the completion of the questionnaire, or if you have any questions or concerns, please do not hesitate to contact me. On behalf of the Mental Health Rights Coalition, I would like to thank you for your assistance.

Yours truly,

Sheona Wilson

Agency Letter, February 20, 1993

The intention of this questionnaire is to assess the current resources for and the needs and concerns of female consumer/survivors in the Hamilton-Wentworth area. The results of this assessment will enable the Mental Health Rights Coalition to address specific, identified concerns of women involved in the mental health system.

Agencies who currently deal with female clients (over the age of fifteen) were chosen to respond to this questionnaire and we hope to have a high response rate from them. Your participation is voluntary, but your input is greatly needed and would be appreciated.

Results from the assessment can be made available, should you be interest. To obtain a summary of the results, please request it in writing from the Mental Health Rights Coalition office at 43 Charlton Ave. East after April 1993. Please send the completed questionnaire to 43 Charlton Ave. East, Suite 104, by March 5, 1993. On behalf of the Mental Health Rights Coalition, I would like to thank you for your assistance. If you have any questions or concerns, please do not hesitate to contact me.

Yours truly,

Sheona Wilson

Appendix B
Consumer questionnaire

Please answer the following questions:

1. What is your present age?
16-19 20-29 30-39 40-49 50-59 60 or older

2. How long have you lived in the Hamilton area?
less than one year 1-5 years 6-10 years over ten years

3. How long have you been a consumer of the mental health system in the Hamilton area?
less than one year 1-5 years 6-10 years more than 10 years

4. Have you even been an inpatient in a psychiatric ward or hospital in the Hamilton area? If so, where?

5. Did you experience any difficulties in making the transition back to the community? Please explain.

6. Were there any services available to you to help with the transition?
If so, what were they? Did you find them useful? Please explain why or why not.

7. What services have you used within the past twelve months?

family physician
medical specialist
hospital emergency ward
psychiatrist
mental health agency
hospital outpatient dept.
hospital inpatient ward
employment agency
employment counselling
credit counselling
private therapist
support group
family counselling
emergency housing
other (specify)

8. Which agencies/services did you find the most helpful? Why?

9. Which were the least helpful? Why?

10. How do you usually find out about existing services in the Hamilton area?

phonebook
pamphlet
family physician
family member
friend
other (specify)

11. Have you ever been denied service at an agency? If so, what was the reason?
geographic area of service
financial
waiting list
service did not meet your needs
other (please explain)

12. In your opinion, are the services currently available in Hamilton sufficient to meet the needs of female consumer/survivors? Please explain.

13. What in your opinion, is needed for female consumer/survivors in the Hamilton area? Please explain.

14. Please add any further comments you may have about existing or needed services in the Hamilon area.

Appendix C
Agency questionnaire

A. Services Provided

1. What are the major services offered by your agency?

2. What percentage of your clients are female? (this may be estimated)

3. What are the eligibility requirements for clients?
none geographic financial age sex other (please specify)

4. Do you provice services to females identified as consumers of the mental health system? If so, what is the estimated percentage of clients identified as consumer/survivors?

B. Personnel Characteristics

5. What specific training, if any, does your staff have with regard to mental health issues or issues concerning primarily women?

6. Do you provide in-service training on these issues? What women's issues in particultar?

7. What is the average client caseload per staff member?

8. Are any of your staff members consumer/survivors?

C. Accessibility, Availability and Awareness of Service

9. What is the location of your agency?

10. Is it located close to public transportation?

11. Is the location geared to a particular target population? If so, what is the target population?

12. What are the working hours for your agency?
Do you provide: after hours emergency service, on-call services, other (please specify)

13. Is there childcare available if needed?

14. How is your agency advertised?
pamphlets/brochures, telephone directory, community services directory, other (please specify)

D. Financial Characteristics

15. Is there a fee for any of your services? If so, what is the fee? Is the fee covered under any existing insurance policies? Do you offer a sliding fee scale?

16. How is your agency funded?
privately government other (please specify)

E. Referrals

17. Approximately how many referrals do you receive for your services over a one month period?

18. What is the source of your referrals (please check all that apply)

self, other agencies, physician, family member, other

19. What are the major reasons for referral to your agency?
geographic area of your agency, geographic area of the client, presenting problem of the client, other (please specify)

F. Clients accepted for service

20 Approximately how many new clients are accepted for service over a one month period?

21. What are the presenting problems of the female clients accepted for service? (please check all that apply)

psychiatric diagnosis
marital/relationship difficulties
alcohol/drug abuse
child management concerns
employment issues
educational issues
medical concerns
family difficulties
past history of abuse
physical, sexual or
emotional
domestic violence
other (please specify)

22. Approximately how many clients have been denied service over the past month?
Reason: not able to benefit, inappropriate for your services, geographic area of the client, age of client, other (please specify)

G. Waiting list

23. Does your agency currently have a waiting list for services?
If so, what are the reasons for the waiting list?
time constraints, lack of staff, lack of resources/funding, increased demand for service, other (please explain)

24. What is the average length of time one is on the waiting list?

25. How many people placed on a waiting list do not eventually receive service?
Reason: found services elsewhere, client chose not to be put on list, other (please specify)

H. Expansion/Growth

26. Are there any services provided by your agency to women which are increasing in demand?

27. If so, are you able to meet this increasing demand?

28 Would you, given the resources, conside expanding your present service if a need were identified?
If so, what would be needed: funding, staff training/eduction, other (please specify)

I. Referrals initiated

29. On average, how many referrals are made by your agency in a one month period?

30. What are the major reasons for the referrals?
presenting problems of the client, geographic, financial, other (please specify)

31. Are there any difficulties in making referrals? If so, are they due to: language, culture, transportation, financial, geographic location of client, lack of appropriate services, other (please specify)

32. In your opinion, is there any need for service not currently available to women in the Hamilton-Wentworth area?

33. If so, what do you think is needed?

34. Further comments:

Notes

Order Form

No Longer a Voice in the Dark

An assessment of the current resources
for and concerns of female consumers
in Hamilton-Wentworth

Send to

Mental Health Rights Coalition
100 West Fifth Street
Hamilton, Ontario L9C 3N6

Telephone: (416) 388-2511, extension 4569
Fax: (416) 388-2566

Please send me _____ copies of "No Longer a Voice in the Dark".

Enclosed is a cheque for $ _____ to help defray printing and mailing costs.
(Voluntary contribution for those who can afford it)

Name Date

Organization

Address

City Province Postal Code

Your comments and questions please

No Longer a Voice in the Dark

We hope this report will encourage meaningful dialogue among women and service providers about the issues raised. Your comments and questions are most welcome. If you would like to be involved in any follow-up work, please let us know.

Susan Roach, Chair of the Board of Directors, Mental Health Rights Coalition

Send/Fax to:

Women and Mental Health Project, Mental Health Rights Coalition
100 West Fifth Street
Hamilton, Ontario L9C 3N6

Telephone: (416) 388-2511, extension 4569
Fax: (416) 388-2566

( ) I would like to be kept informed of any follow-up to this report

( ) I would like to be involved in any follow-up to this report

Comments/Questions (please use additional sheet of paper if more space is required)

Name Date

Organization

Address

City Province Postal Code